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## **Gaining ethical approvals to undertake sexual health research with young people in the UK: Applying a 'Children's Rights Based Approach'**

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**RN-16 Newsletter**  
**Issue 4**

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## Welcoming from the RN-16 Newsletter Co-Editors

Dear colleagues,

The first **PhD Workshop** ‘Ethics and methodological pitfalls in health research’ organised by our research network **took place in Helsinki in the later August** and seemed to us to be a good occasion for a Special Newsletter Issue. In this newsletter you will then find a brief **summary of the PhD Workshop**.

The **next ESA-Conference** will be held **25<sup>th</sup>-28<sup>th</sup> August 2015 in Prague**. We look forward to a vibrant series of RN-16 sessions at ESA-Conference and we would like to invite you to submit an abstract of your more recent work. The call for papers will be **launched 28<sup>th</sup> November 2014**.

Updated information will be regularly provided on the **ESA-Conference website** so please have a look on the link: <http://www.esa12thconference.eu/>

Your collaboration is essential for our newsletter therefore **we invite you to share your ideas or suggestions about our future activities**. Please feel free to write us to email address below.

We would also like to invite you to **renew your membership for RN-16 and ESA**, as this is vital for the success of our Research Network, namely in the planning of future events and activities.

Enjoy the reading!

Ana Patrícia Hilário& Micol Pizzolati

**RN-16 Newsletter Co-Editors**

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## **RN-16 PhD Workshop**

*The European Sociological Association, Research Network on Sociology of Health and Illness  
(ESA RN-16) in cooperation with the ESHMS and ISA RC15*

### **‘Ethics and methodological pitfalls in health research’**

**Held on 27<sup>th</sup> August 2014 prior to the joint ESA RN16, ESHMS and ISA RC 15  
Conference in Helsinki, Finland**

Whilst investigating the domain of health and illness in the lives of people and modern societies, medical sociologists have always dealt with various aspects of human suffering. Correspondingly, perhaps more than their colleagues working in other fields, they have been faced with specific ethical and methodological questions related to such conditions. However, the specific nature of these issues is rarely a matter for wider discussions in this sub-discipline.

This PhD workshop addressed the need to discuss ethical and methodological questions particular to the field of sociology of health and illness, with a specific aim of helping social science doctoral students and young researchers working in the field, to find appropriate ways of dealing with ethical and methodological dilemmas in their research. The workshop participants get an opportunity to engage in discussions about their current research projects with other student colleagues as well as with prominent scholars in the sociology of health and illness who assist them as mentors.

There were several working groups focussing on topics such as:

- Researching vulnerable populations
- Dealing with ethical committees and writing about ethical dilemmas in health research
- Writing up on and publishing about sensitive topics
- Methodological pitfalls in investigating sensitive topics
- Ethnography in medical settings: ethical and methodological dilemmas

#### **Eligibility:**

Social science PhD students and young researchers working in the field of health and illness were eligible to apply.

#### **The Venue:**

The PhD workshop was co-organized with the ESHMS, ISA RC15 and the University of Helsinki, Finland.

**Programme ESA RN16 PhD Workshop ‘Ethical and methodological pitfalls in health research’  
27<sup>th</sup> August 2014 Helsinki, Finland**

<b>9.00-9.30</b>	Registration	
<b>9.30-10.30</b>	Introductory note <b>Prof. Ellen Annandale:</b> <i>Writing up and publishing on sensitive topics</i> Key note lecture and discussion	
<b>10.30-11.00</b>	Coffee Break	
<b>11.00-12.30</b>	<b>Session 1:</b> <b>Mentor:</b> <i>Ellen Annandale</i> 1. E. Helosvuori: <i>‘The Devil is in the Details’: Negotiating the Art of Embryo Selection in IVF</i> <b>Discussant:</b> <i>M. Templeton</i> 2. R. Lotto: Termination of pregnancies due to fetal anomalies <b>Discussant:</b> <i>E. Helosvuori</i> 3. M. Templeton: <i>Gaining Ethical Approvals to Undertake Sexual Health Research with Young People in the UK: Applying a ‘Children’s Rights Based Approach</i> <b>Discussant:</b> <i>R. Lotto</i>	<b>Session 2:</b> <b>Mentor:</b> <i>Karen Lowton</i> 1. J. Belcher: <i>Complex needs: the ethics of research practice with parents of people with a rare syndrome</i> <b>Discussant:</b> <i>M. Webster</i> 2. J. Swallow: <i>The Role of Instruments for Screening Cognitive Function and Alzheimer’s disease: NHS Ethics, ethnography and the negotiation of ontological concern</i> <b>Discussant:</b> <i>J. Belcher</i> 3. M. Webster: <i>The Difficulties of Accessing Children’s Health Experiences</i> <b>Discussant:</b> <i>J. Swallow</i>
<b>12.30-13.30</b>	Lunch	
<b>13.30-14.00</b>	<b>Prof. Jonathan Gabe:</b> <i>Ethics and methodological problems around sensitive research</i> Key note lecture and discussion	
<b>14.15-15.45</b>	<b>Session 3:</b> <b>Mentor:</b> <i>Jonathan Gabe</i> 1. S. Uusitalo: <i>Researching the research on heroin addiction</i> <b>Discussant:</b> <i>P. Vasilyev</i> 2. P. Vasilyev: <i>Dealing with Ethical Dilemmas in the History of Drugs</i> <b>Discussant:</b> <i>S. Uusitalo</i>	<b>Session 4:</b> <b>Mentor:</b> <i>Piet Bracke</i> 1. M. Geisler: <i>The story of autism in the Czech republic: methodological and ethical aspects</i> <b>Discussant:</b> <i>O. Shek</i> 2. A. Lorette: <i>Social inequalities and cancer in Nord-Pas-de-Calais in France</i> <b>Discussant:</b> <i>M. Geisler</i> 3. O. Shek: <i>Doing qualitative research in post-Soviet mental health services</i> <b>Discussant:</b> <i>A. Lorette</i>
<b>15.45-16.15</b>	Coffee break	
<b>16.15-17.15</b>	<b>Session 5:</b> <b>Mentor:</b> <i>Guido Giarelli</i> 1. L. Coulomb: <i>Healthcare workers and homeless people</i> <b>Discussant:</b> <i>K. Bermudez</i> 2. K. Bermudez: <i>Engaging ‘socially distant’ undocumented migrants in health research</i> <b>Discussant:</b> <i>M. Roriz</i> 3. M. Roriz: <i>Complex truths at the hospital. How may different ethos collaborate for the sake of health?</i> <b>Discussant:</b> <i>L. Coulomb</i>	
<b>17.15-18.00</b>	Concluding discussion and remarks	

## ESA RN16 PhD Workshop Report

### Ema Hrešanová



Assistant Professor  
University of West  
Bohemia

As a sociologist investigating such intimate matters as reproductive health, I have always been very aware that ethical conduct in sociological research on health and illness is critically important. Every step in research - from conceiving the idea to publishing findings - implies particular ethical questions. Thus ethical and methodological questions are closely intertwined.

Therefore, I was very excited by the opportunity to organise a workshop on these issues for junior colleagues. The thematic focus met with substantial interest among PhD and Post-doctoral researchers. We received more than thirty applications while being able to accommodate only half of this number.

The one-day workshop took place prior the joint ESHMS, ESA RN16 and the ISA RC15 conference in Helsinki. The format of the workshop allowed participants to present their research findings and related concerns in a written as well as oral form. This, I believe, generated rich discussions beneficial for both the presenters as well as other attendees.

The diversity of topics also turned to be enriching. We could learn from a number of papers addressing similar ethical or methodological issues in relation to diverse subjects. Various cultural contexts shaping academic research turned to be important, too, as our discussions highlighted diverse formal ethical standards across the European countries. Participants were at various stages of their research projects. While some PhD students presented elaborate analyses based on long-term fieldwork, others were at the very beginning and took advantage of this forum to discuss particular methodological issues they struggled with in their research projects.

Our acknowledgements especially go to five mentors who agreed to chair the sessions, and who read and commented on presented papers. Their work and knowledge was truly essential for the workshop's success. Thank you, Ellen Annandale, Jon Gabe, Piet Bracke, Guido Giarelli and Karen Lowton!

We would also like to thank the European Sociological Association, (especially the Committee for research networks), whose conference grant allowed this all happen. Moreover, with the support of the ESA, the RN16 was able to provide a fellowship to one participant to cover travel costs.

We generally received a very positive feedback on the quality of the workshop. This encouraged us to make a promise to the Global Health Initiative associations that we will do it again. We believe that a separate event dedicated to work of our junior colleagues, held either before or after the mid-term conferences or the biennial congresses, will be beneficial not just for our research network but for the whole community of medical and health sociologists. We make plans to hold the next event prior the Prague conference in August 2015.

If I were to change anything about the PhD workshop in Helsinki, I would have asked for more time. So many interesting research projects, so many new enthusiastic researchers and just little time to learn about both! It is my wish that the next ESA RN16 PhD workshop provides many more formal but also informal opportunities to exchange ideas and to talk about research interests which we all share.

## Keynote Speaker Professor Ellen Annandale

### *- Journal Publishing and Ethics –*



Professor Ellen Annandale  
University of York

The presentation addressed the following main themes: recent developments in journal publishing; how to get published in the journal of your choice; and journal publishing ethics and some special issues associated with research on sensitive topics. In what follows, I briefly outline some of the issues raised under each theme.

#### *Developments in journal publishing*

One of the main changes in the journal world has been the fast-paced development of ‘open access’ publishing. Although it is an over-simplification, one way to understand this is a move from a ‘reader pays’ to an ‘author pays’ model. In other words, under open access authors pay the journal/publisher to make their paper available at no charge to readers as they do not need to be subscribers to access the paper (payment takes place at the point acceptance, not when you submit).

This is often known as ‘gold open access’. Many new open access-only online journals have started up in recent years (especially in the STEM subject area). While some provide rigorous peer-review and are high impact, is it not always the case. Long-standing, ‘traditional’ journals which are available as print/hardcopy and via online access, such as *Social Science & Medicine*, and *Sociology of Health & Illness* offer authors the option to make their article open access for a fee (fees vary but can be around US\$3000) or to make it only accessible to subscribers. ‘Green open access’ refers to the self-archiving of a published article, such as in an institutional repository, e.g. of a university.

Although it varies by journal, the publishing process has become faster-paced as authors expect and require faster turn-around from submission of a paper to its citable publication. The volume of submissions also keeps rising (though not necessarily of high quality papers). This puts pressure on journal editors whose publishers may expect increasingly swift review processes and editorial decisions. One issue to consider is whether this is leading editors to be less ‘hands-on’ in their support of the editorial process e.g. they have less time to provide detailed letters to authors alongside review reports. Finally, as discussed later, there have been growing concerns about publishing ethics and matters of integrity from authors, readers, editors and publishers alike.

#### *How to get published in the journal of your choice*

It is important to be aware that acceptance rates of the top journals in the health sociology field and beyond are quite low, e.g. less than 18% of submitted papers may eventually be accepted. It is important not to be put off by this however, and to aim for the best journal that fits the content of your paper. In fact this is one of the most important choices to be made: which journal to submit to? You need to ‘know your journal’; read the papers it has published, look at editorials (which may signal the kind of work the editor(s) is seeking), and pay close attention to a journal’s aims and scope statements. The length of paper that the journal allows may also be a deciding factor for you. The sources of advice are of course obvious: PhD supervisors, PhD examiners, journal editors (you may meet them at conferences, for example). While this seems self-evident, it is important to only submit your paper when it is the very best it can be. It might be tempting to think, ‘it’ll only need to be revised anyway, so I may as well submit it rather than spend more time on it’. But this strategy may



risk a quick rejection.

As a former journal editor (of *Social Science & Medicine*) I always advised new authors to make what is *novel* in their paper (results, theory, both) as clear as they could. It is all too easy to think that because you know what is ground-breaking in your analysis that the editors and reviewers will too. But this may not be the case at all as editors and reviewers are not likely to be experts in every area of health sociology, not even within sub areas. It can even be advisable to include a direct sentence actually telling the reader what is novel at the start of your paper (some journal may ask for a covering letter which outlines this too).

While the publishing process has speeded up with the advent of new technologies for manuscript handling and technical processing, the review process can still sometimes not be as quick as we would like as authors. Many journals now operate strong initial triage processes whereby they rule out (reject) papers that they feel do not have a strong chance of successfully passing the peer review process. While it might seem kinder to instead give more authors 'a chance', it can be said that if that chance is slight then it is better to release the paper for submission elsewhere as quickly as possible. If papers pass triage they normally will be sent out to two or more reviewers for their assessment. Based on these reports an editor will make a decision to either accept a paper as it is (very unusual for top journals), ask for minor revisions, ask for major revisions, reject. Journals will send the reviewers' reports to the author, sometimes accompanied by a summary from the editor. If the paper is to be revised, you will usually be given a date by when this should be completed (though it may be possible to ask for an extension to this). If you are asked to revise it is important to take this very seriously and not to assume that this means the paper will eventually be accepted (a revision is, for example, likely to go back to your reviewers). You will need to address all the reviewer comments and may be asked to provide a document outlining how you have done this. You might not agree with all of the reviewer requests. They may, for example, have misunderstood aspects of an analysis. If so, it is fine to explain this (respectfully of course!). Some journals have published appeal procedures for authors who disagree with a reject decision on their paper, but this isn't very common. If you feel strongly that the wrong decision has been made and you have good reason (it can be worth asking colleagues for input) then you might contact an editor and politely request a reconsideration. In my experience this is not commonly done however.

It is worth reflecting on why papers tend to get rejected. The reasons could vary journal-by-journal, of course. In from my perspective the following are critical (in no particular order): not in scope for the journal; badly written/unclear argument/disorganised/lacks a clear message; 'reinventing the wheel', nothing really novel; no sense of why the issue addressed is important to the field/for advancing the field; poor knowledge of the existing relevant literature; and for empirical analyses, weak and/or poorly explained methodology.

### *Journal publishing ethics*

The main overarching issues covered in this part of the talk were: editorial processes and standards, and things that authors need to be aware of. Journals now have clear guidelines on what constitutes ethical practice (on the part of editors as well as authors) and how ethical violations should be dealt with. The Committee on Publication Ethics (COPE) to which many journals belong is 'a forum for editors and publishers of peer-reviewed journals to discuss all aspects of publication ethics. It also advises editors on how to handle cases of research and publication misconduct'. COPE can be viewed at <http://publicationethics.org>. COPE outlines reporting standards which, to paraphrase, explain amongst other things that authors should present an accurate account of their work (to avoid fraudulent use of data) as well as an objective account of their significance (to avoid fraudulent claiming). Journals usually place a number of duties on corresponding authors at the point of submission. The expression of these may vary but often include an endorsement that the paper is not under consideration by another journal (sometimes referred to as concurrent publication), that its contents are original (i.e. that they have not been already published elsewhere); that empirical research has been subject to appropriate ethical review (and if not, why not); and that all authors meet

authorship requirements. It is important to look very carefully on these matters when submitting a paper. Let's reflect in particular on who qualifies as an author because while on first glance this may seem obvious, it may not turn out to be as straightforward as it seems. Many journals (not just medical journals) follow the guidance of the International Committee of Medical Journal Editors (or ICJME) <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>:

“The ICMJE recommends that authorship be based on the following 4 criteria:

- Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- Drafting the work or revising it critically for important intellectual content; AND
- Final approval of the version to be published; AND
- Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved”.

Here it is important to note the use of ‘AND’, that is, *all* of these criteria should be met. One of the reasons why it is necessary to spell things out in this way is to avoid what is colloquially known as the unethical practices of ‘ghost’ and ‘gift’ authorship. The former refers to when an author who should have been included is left out and the latter to when an author is included who should not have been. ‘Gift’ and ‘ghost’ have tended to occur in situations of power where, for instance, junior staff on a project are left off authorship when they should have been included and when senior staff put their names (or have their names put on) work when they do not qualify for. Criteria like those of ICJME can help with these practices, though they are not a complete solution. Authorship disputes are not uncommon and often arise in the context of team working on a large project. One way of trying to avoid them is being clear within the team on authorship criteria from the start of a project.

As noted above, one of the most important ethical issues to reflect on is that your paper's content is original. There are at least two dimensions to this. The first is that it must be your own original work and not someone else's. Instances of plagiarism are increasingly coming to light, although it is hard to know whether this is because more plagiarism is occurring or whether it is now more likely to be detected due to powerful software tools. Many journals make use of software such Crossref, which is a text-matching tool <http://www.crossref.org/>. Thus papers can be checked at submission for undue overlap with work in the public domain. But plagiarism can also come to light in the course of the review process, being picked up, for example, by reviewers. Plagiarism brought to light before a paper is published may be reported to an author's employer; plagiarism brought to light once a paper is published can lead to public retraction. The second dimension of ‘original content’ is that you should not have published it already elsewhere yourself. While duplicate publication (sometimes known as self-plagiarism) is obvious, what counts as ‘original’ can be hard to call. Most journals see it as unethical, for example, to engage in what is known as ‘salami slicing’, that is, cutting the results of a project into very small slices which are to a very large degree more or less the same and publishing them in a number of articles, or ‘refried beans’; rehashing the same results over and over again and publishing them in different words. But at the same time it is recognised that a large project, such as a PhD study, with a large ‘data set’ will generate a series of connected outputs of various kinds. If there is doubt about ‘originality’ it is probably best to contact the journal editor in advance to alert them of cognate papers that you have published (indeed, some journals will ask you to declare them at the point of submission).

#### *Some special issues associated with research on sensitive topics*

Since the topic of the pre-conference event was research on sensitive topics, some brief reflection was given in the keynote on the implications for publishing. Issues raised included the following. First, the challenges of gaining Ethical Committee approval for sensitive research alongside the

requirement of many journals in the health field that your university or other body has given approval to your research for it to be published. The ethical approval process was a topic covered in detail by Jonathan Gabe in his keynote. In my talk it was specifically noted that ethical approval requirements for research with ‘human subjects’ varies considerably from country to country, with some countries requiring any research which involves humans to be ethically approved and others only needing this when patients are involved. It was also remarked upon that that challenges can arise when researching in different countries (to where a researcher works). For example, is it ethical that an ethical committee in one country gives permission for a researcher to conduct research elsewhere, or do ‘local’ ethics committees (which may have different rules) also need to be consulted? It may be necessary to outline this in the methodology sections of articles so that decisions and the reasoning behind them are made transparent. Second, and sometimes allied to ethical approval, it was discussed that it may not always be easy, or even advisable, to ensure confidentiality (concealing identities) and/or anonymity (right of access to data) to research respondents. Obviously this needs to be thought of prior to publication. Third, and finally, it was noted that some research is not only ethically but also politically sensitive. In the health field the obvious example is research on tobacco companies and pharmaceutical companies. Since tobacco and pharmaceutical companies may keep a close watch for publications which make reference to their products, journals may make legal checks of papers on these topics to ensure that they do not contain libellous, publishing defamatory material (e.g unsupported claims of corruption or incompetence). Here it is worth observing that libel law varies between countries so the ‘sensitivity’ of an article content may vary according to where a journal is published.

In overall conclusion, publishing ethics and publishing ethically sensitive research is a broad and complex topic which does not always have straightforward guidelines. It hasn’t been possible to go into all of the issues in this short piece, but hopefully the points raised provide a basis for reflection.

## Keynote Speaker Professor Jonathan Gabe

### *- Ethical and Methodological Problems around Sensitive Research in Health -*



Professor Jonathan Gabe  
Royal Holloway,  
University of London

When I started my first job, as a social researcher interested in health issues, in 1979 ethics was of less concern than it is today. At that time one did not need to apply for ethics clearance to do research with patients and their doctors – it was assumed one's research would be ethically informed because of the reputation of the university one was working for. How times have changed. Now, it is a major issue for social researchers and involves a considerable amount of temporal and emotional investment. In the UK it typically involves seeking ethics clearance from a university or university department research ethics committee (REC) and in cases of research in health care settings, from the National Health Service Local Research Ethics Committee (LREC). Typically RECs/LRECs are not disciplinary specific and cover any research with human subjects

These ethics committees have one thing in common. They are all based on the principles of bureaucratic rationality – with the research being judged on the basis of apparently transparent, bureaucratic rules and regulations. The reason for such rules, it is argued, is the need to protect both the research subjects and the researcher.

These bureaucratic rules need to be placed in a global context where ethics in social research, or McEthics as it has been called (Melrose 2011), are shaped by ethical values first formulated for and applied to biomedical research in the United States. Such developments have been characterised as 'ethics creep' (Haggerty 2004) because of the increasing intensity of REC scrutiny and what it symbolises; namely the growth of bureaucratic control and the institutionalisation of distrust of researchers seeking responsibly to go about their work.

It has also been argued that ethics regulation is based on a culture of fear about the possible threat of research to the reputation of universities and health service organisations. This has resulted in what Haggerty (2004) calls 'precautionary decision making', where the focus is on 'what if' or worse case scenarios, rather than considering what is likely or probable if a particular piece of research is undertaken.

We can identify two basic stances on ethics, universalism and situation ethics (Bryman 2012). Those who take a universalist position believe that ethical principles should never be broken as to do so would be both morally wrong and damaging to the reputation of social research. Those who advocate situation ethics suggest that ethical decisions are in reality made or negotiated on a case by case basis, depending on the circumstances.

In the remainder of the talk I took two examples of REC applications to illustrate the explanatory value of the situation ethics stance. First was an LREC application by a PhD student to undertake an ethnographic study of pain management on a children's ward. And second was a REC application by a postdoctoral research fellow to conduct an interview based study of children and young people's experience of asthma. Both these cases revealed how decisions about ethics were informed by the precautionary principle which resulted in considerable delay. Both involved negotiation and re-interpretation and showed how REC decisions are often local, specific, processual and contestable. It was suggested that RECs need to be more reflexive and critical about the unintended consequences of their rule following and that social researchers should try to contest ethics creep and, given the reality of RECs, should argue instead for a simplified process which still places the safety of research subjects and the researcher centre stage.

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## PhD Students (Alphabetic Order) Short-Bio and Abstracts

### Aurore Lorette



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I am a PhD researcher in the Sociology department at the University of Lille1. My doctoral research is on cancer and social inequalities in Nord-Pas-de-Calais Region in north of France. This Region has a significant number of new cases and an annual mortality well above the national average. The aims of this research is to contribute to the understanding of the processes and mechanisms involved in the formation of social inequalities chances of survival, survival times and mortality with cancer in Nord-Pas-de-Calais Region. I mobilize a qualitative methodology with the aim of understanding the pathways and experiences of people who have experienced cancer in relation to their social conditions of existence.

### Social inequalities and cancer in Nord-Pas-de-Calais in France

Our doctoral research is on cancer and social inequalities in Nord-Pas-de-Calais Region. With 355 350 new cases and 148 378 deaths, cancer is the leading cause of death in France. The Nord-Pas-de-Calais Region has a significant number of new cases and an annual mortality well above the national average. Regional mortality excess, as Pierre Aïach demonstrated, is mainly due to social inequalities in mortality, which is 60 % for category employed-workers against 9% for the category of white collars. Social inequalities in cancer are now a real public health concern, since they have increased over the last thirty years and are responsible for a significant avoidable mortality. In Nord-Pas-de-Calais Region, it is almost 2043 on 10 000 deaths that could be avoided (in 2013), if the regional mortality was equal to the French average. The aims of this research is to contribute to the understanding of the processes and mechanisms involved in the formation of social inequalities chances of survival, survival times and mortality with cancer in Nord-Pas-de-Calais Region. These mechanisms are complex due to various and intricate factors at different stages. Most of the research studies on social inequalities in cancer are quantitative. This research mobilizes a qualitative methodology with the aim of understanding the pathways and experiences of people who have experienced cancer in relation to their social conditions of existence. These field works are complementary since they allow to analyse different populations in various contexts. We interviewed patients and some professionals. Exploratory interviews have been realized with professionals. With patients we explored their experiences and trajectories in relation with their social conditions of existence, in the frame of a comparative perspective. A particular attention is therefore paid to the social diversity of the sample of the people interviewed. Meanwhile medical consultations were observed in two different hospital departments of the Region: senology and head and neck cancer out patients' departments. We also studied support groups and associations for patients. This research put forward ethical and methodological problems relating to the concern of social definition but also social diversification of the population during our research. We are confronted, in our field work, with a major challenge: how can we come across social diversification in our research? Therefore, our population study is biased, since it is mostly made up of women aged fifty years and more, suffering from breast cancer and having a long experience of illness. To meet men and disadvantaged populations is even more difficult. This difficulty to obtain social diversification is an important issue for our research. A second issue is about the social definition. What is a social context ? How can we figure it ? How can we have a comparative approach of the patient's trajectories without falling into the pitfall of a binary representation of society with on one hand the "privileged" ones and on the other hand, the "disadvantaged" ones? That representation hides the social gradient that characterizes the social inequalities in health.





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I work as a doctoral student at the University of Helsinki, the Department of Social Research. My PhD research project focuses on infertility in contemporary high tech society. My research interest areas are sociology of the body, sociology of health and illness, science and technology studies, gender studies, and materialism. I receive funding (2014–2017) from the doctoral programme Gender, Culture, and Society (<http://www.helsinki.fi/sky/index.html>). In addition, my doctoral project's main site of research is the project *Pluripotent Science: Use of stem cells in the creation, assistance and prolonging of lives* directed by PI Mianna Meskus (University of Helsinki) and funded by the Kone Foundation (<http://blogs.helsinki.fi/pluripotentscience/>). I am an active participant in the *Biomedicine in Society (BitS) Research Platform* (convened by Docent Ilpo Helén, University of Helsinki), which brings together scholars in social sciences of biomedicine at the Department of Social Research. The main result of my PhD project is an article dissertation conducted in English. I have published my first article in a Finnish refereed journal *Sosiologia* 50:3, Special Issue on Materiality (Helosvuori, Elina (2013) Joustava luonto hedelmöityshoidoissa [Flexible Nature in Infertility Treatment]). *Sosiologia* [Sociology] 50:3, 239–254). I am currently preparing my second article manuscript. In addition, I have published a popular article in the journal for the members of The Finnish Infertility Association.

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### **“The Devil is in the Details”: Negotiating the Art of Embryo Selection in IVF**

This paper explores the practices of selection entailed in IVF-treatment. Here, selection refers to picking the most vital embryo to be transferred to a woman's womb in infertility treatment. The paper draws from the ongoing ethnographic fieldwork conducted in a private IVF clinic in the metropolitan area of Finland. In addition, I have participated in peer support groups for patients, operating through Internet forums and in patient organizations. The fieldwork in the meetings of four face-to-face peer support groups took place from November 2013 to May 2014. In addition, I draw from 11 semi-structured interviews completed with women who have experienced infertility and IVF. Using the methods of multi-sited ethnography and science and technology studies, I analyze the negotiations between doctors, IVF-biologists, geneticists and patients concerning the question of how to select an embryo that is most likely to result in a pregnancy. In addition, I discuss the ethics of my methodological choices. As a case study, I follow the implementation of the *Time laps* -computer and embryo storage -program and chromosomal testing of embryos for discovering genetic abnormalities. I refer to the extending body of sociological literature on prenatal genetic diagnosis/screening (PGD, PGS), mainly discussed in relation to sex selection of embryos and screening of hereditary illnesses. However, I suggest that the *mundane* practice of applying these experimental technologies to *routine* IVF treatment is now taking place. I argue that these technologies change the ways in which patients undergoing IVF justify, problematize and understand embryo selection. In addition, I suggest that hopes, fears and dilemmas experienced by the patients have already started to intertwine with these technological practices currently arriving in Finland.



I am an ESRC-funded PhD researcher in the Sociology department at the University of Surrey. I am researching the role of online support for parents of people with Rett syndrome. My research interests include caring, complex health needs, disabilities, social capital and online support. The charity Rett UK provides external supervision. Before beginning my PhD I worked in a range of voluntary and public sector roles, which has included work to support carers and people with learning disabilities, mental health problems and complex health needs.

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### **Complex needs: the ethics of research practice with parents of people with a rare syndrome**

This paper explores some ethical dilemmas faced while carrying out sociological health research with parents of people with a rare syndrome associated with complex health needs. I discuss how I negotiated four ethical dilemmas during my PhD research into the role of online support for parents of people with Rett syndrome. Firstly, managing the risk of exploitation in an over-researched and under-pressure group where some parents report agreeing by default to any form of research. Secondly, finding the line between encouragement and intrusion throughout the process of recruitment. This focuses on the difficulties of ‘following up’ parents of people who regularly experience unpredictable and potentially life-threatening health problems. Thirdly, dealing with the tension between the sociological need to present a syndrome as a case study to illustrate wider arguments and parents' expectations of a contribution to the awareness and understanding of a specific syndrome. Finally, finding a balance between the needs of the researcher and the interviewee in managing the focus of interviews. Particular attention is paid to an interview where the interviewee repeatedly shifted the focus toward a cathartic exploration of traumatic experiences that were contextually but not directly linked to the topic under study. These four dilemmas are used to argue that in research with parents of people with rare syndromes it is necessary to go beyond informed consent, to reappraise continually the potential for exploitation and harm and to be prepared to allow participants to influence and change one's conceptions of the benefits and uses of one's research and research process.





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I am a PhD researcher in the Sociology and Social Policy department at the University of Leeds and the Science and Technology Studies Unit (SATSU) at the University of York. My research is funded by the ESRC as part of the White Rose Doctoral DTC studentship network, 'Rethinking the social production, locus and impact of bioscience' and explores the role of instruments for screening cognitive function in the process of diagnosing Alzheimer's disease across clinical and policy practice. My thesis encompasses the Sociology of health and illness and Science and Technology Studies (STS). I hold a BA in Sociology from the University of Liverpool and an MA in Social Research from the University of York.

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### **The Role of Instruments for Screening Cognitive Function and Alzheimer's disease: NHS Ethics, ethnography and the negotiation of ontological concern**

The 'ageing population' in the UK, reflecting an increase in individuals over the age of 65 (Rajah, 2009), has firmly established the prevalence of Alzheimer's disease as a site for concern in social policy and medical research and practice (DoH 2012; MRC NMHB, 2013). Despite the plethora of highly technological, innovative techniques in research such as biomarker technologies, there is continued reliance in clinical *practice* on the use of relatively simple instruments for screening cognitive function. These instruments are used to aid further diagnostic testing by clinicians. Yet the uncertainty associated with both a diagnosis of AD and the conditions in which these instruments exist (Newman and Feldman, 2011) requires exploration. There is a lack of research however, on their role and employment by clinicians in this arena of uncertainty. This PhD research is concerned with healthcare practice; adopting an ethnographic case study approach drawing on the work of Anne-Marie Mol (1998), employing qualitative methods including participant observation and interviews across healthcare practice. The focus of this paper is on the UK NHS ethics process which may have the potential to constrain research methodology. The research design becomes a collaborative endeavor with clinicians to ensure alignment with the concerns of the NHS ethics process; subsequently the design becomes in part bound to the ontology of committee. This paper explores how this may have the potential to limit the extent to which research is able to be wholly ethnographic in approach; prior assumptions about what to look for and engage with are made. Addressing the ontological concerns of ethnography and constructivist accounts of practice in STS, and ensuring the research is carried out 'ethically', requires negotiation. Attention will also be given in this paper to 'ontography' as a way of avoiding such subscription to a particular ontology or ontologies (Lynch, 2013).



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As a community psychologist, I have been working in international conflict/post-conflict environments addressing the psychosocial consequences on individuals and collectivities of social breakdown and persisting lack of social cohesion. These professional experiences provide the basis for a particular interest in cultural diversity issues and their impact on individual social adjustment. During the post-2008 global economic crisis period in my home country, Spain, a relevant issue in this regard concerns the particular impact of this crisis on vulnerable groups of undocumented migrants, as it provoked the dissolution of their available social networks within which they found crucial support for adaptation to the new cultural context. Since this unexpected loss gave rise to numerous challenges that threatened their health and psychosocial wellbeing, for my PhD research I engaged with a small group of undocumented migrants from North and Sub Saharan African countries who were residing at an emergency accommodation in Barcelona consequent to this crisis in order to understand how this experience affected their capacity to rebuild their social support base. Preliminary findings highlight the relevance of trust as a critical mediating variable in social connection when individuals are exposed to highly stressful life environments. These findings suggest that learning about the determinants of continued trust in challenging life contexts can be useful to orient psychosocial support interventions that aim to promote migrant social adjustment and integration.

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### **Understanding the observed variation in patterns of social functioning among a group of undocumented migrants living at an emergency shelter in Barcelona, (Catalonia) Spain**

The 2008 global financial crisis resulted in a major setback for many undocumented migrants from North and Sub Saharan African countries living in Barcelona, Spain, by causing the dispersal of their informal social networks. In order to sustain their migratory project, many resorted to temporary crisis accommodation, and had to rebuild their essential social supports from these shifting grounds. A preliminary enquiry into migrant responses to this situation at one of Barcelona's emergency shelters revealed that one of the hostel administrative staff's major concerns was the observed variation in residents' inclination to broaden their support base in this changed environment. Those whose social circle remained constricted showed signs of poor health: physical complaints, depressed mood, dependency, and anger. This PhD research study, therefore, seeks to clarify the mediating factors underlying the observed variation in individually displayed patterns of social functioning among a small group of 15 undocumented migrants and asylum-seekers residing at the identified emergency shelter. It is hoped that this understanding will provide further insight into key factors supporting migrant social connectedness, as should be considered in the design of psychosocial interventions aiming to address migrant health issues. This study is based on a 5-month participant observation carried out at the emergency shelter in Barcelona where study participants were residing in 2010. Access to this site was made possible after agreeing with shelter administrators to provide psychosocial support to study participants on a voluntary basis throughout this period. This combined service provider-researcher role gave rise to certain ethical and methodological challenges that I would like to discuss during the workshop. As a psychosocial support practitioner-researcher, my concentration has been on restoring social cohesion in contexts affected by social breakdown and chronic instability, as required to rebuild a health-enhancing life environment that is conducive to development. This work essentially involves re-establishing local solidarity networks in partnership with local actors to mediate factors creating further social division and violations of human rights. With this particular focus, I have collaborated with numerous humanitarian aid projects in various conflict/post conflict countries around the world, mainly in Sub Saharan Africa and the Near East. My most recent work assignment (completed at the end of March 2014) has consisted in leading a research consultancy in Goma, North Kivu province, Eastern DR Congo as part of a multi-country research study sponsored by UNICEF on the effectiveness of *Child Friendly Spaces* to enhance child protection and psychosocial wellbeing in internally displaced people camps.

## Laureline Coulomb

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I'm 25 years old and I began research on subjects related to homeless people since my third year of studying sociology. I first worked on homeless people's relationship to time and now I'm particularly interested in the field of health.

My research is inspired by my militant involvement in the care of people living in precarious conditions.

Research interests: homelessness, health, interactions, misunderstandings, conflicts, vulnerability, relationship to time.

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### Healthcare workers and homeless people

Homeless people are entitled to French Social Security benefits, yet they often have poor health. My research will try to understand the various modes of caring for homeless people. I use participant observation in different health structures (hospitals, free clinic, residential care facilities...) and semi-directive interviews with both homeless people and healthcare workers (doctors and nurses). The first results show that healthcare workers and homeless people have different perceptions of health, illness and body image, which can cause misunderstandings and affect the care of homeless people. Healthcare workers often encounter difficulties understanding the demand of homeless people regarding their health. Most of the time, they are refractory to exposing their damaged bodies and they may decline the help they are offered, whatever form it takes, in order to avoid the difficulty exposing their troubles. Analyzing the interactions between homeless people and healthcare workers displays how different their respective logics of action are. But participant observation may affect their interactions. The presence of a third party could influence their behavior, and I'm often asked to participate to facilitate mutual comprehension. So, I'm wondering to what extent I am permitted to help them understand each other. The ethical dilemma deals with the intervention or nonintervention in their interactions. On one hand, this intervention could allow for a better medical care for the homeless people who I've been involved with: I'm well aware of their personal situations, which gives me the opportunity to complete any missing social or medical elements, or to respond to the questions they may not be able to answer. On the other hand, I'm wondering to what degree my presence could change the behaviors I would like to study, knowing that the participant observation is the best way to get as close as possible to their interactions.

## Marta Roriz

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Marta Roriz is a PhD candidate at CIAS – Research Centre for Anthropology and Health in University of Coimbra, with a Master’s degree in Medical Anthropology. She was also a junior researcher at CES - the Centre for Social Studies at the same university, for 3 years. Her previous work relates to health governance and social collectives, biopower, biosociality and biocitizenship. Currently her research interests relate to critical approaches such as political economy in determining health and disease. Her current work focuses on how technology, social organization and policy domain have been shaping the obesity phenomenon.

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## Ethical and Methodological Juxtapositions in a Multi-Sited Ethnography of Obesity Proposal

This paper concerns a PhD project who aims to trace a genealogy on the construction of obesity medical category and the “obesity epidemic”, analyzing it as a public health problem that transcends biomedicalization. Biomedicine, whose tendency is to isolate and study diseases as distinct from their social contexts, transforms social structure problems in individual problems subjected to medical control; hence obesity needs more systemic approaches. Anchored on the critical medical anthropology approach the project aims to analyse obesity as constituted by an intersection of political economy with bio and eco-social causation, pointing out new objects and spaces for health research and intervention, namely on manufactured risks such as contemporary food supply, its liberalization and regulation. The association of obesity to disease risk is a key component on public health discourse on individual’s responsibility for their disease. But it is necessary to examine the limits of this responsibility, once a “persecutory health” is taking place. The obesity epidemic is articulated in a multiple network of actors, different kinds of expertise and discourses, but its treatment occurs in clinical settings. The project relies on multi-sited ethnography in order to collect and account the positioning and experience of different actors taking part on obesity treatment and intervention. Fieldwork will be conducted at Coimbra’s Hospital, but also combines and moves from different bodies of knowledge such as social epidemiology, health political economy, policy studies to better provide and elicit new spots for intervention. Once at the Hospital settings, ethical questions emerge, as well as necessary negotiations. Given that it is the biomedical research ethical model at play, what views on social sciences methods emerge? How are they sometimes limited by ethical committees? Ethics might have to be understood as a field of power and counter-powers given the different *ethos* at stake.

## Michal Geisler

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A Czech Ph.D. student of the Faculty of Humanities at Charles University in Prague, Czech Republic (Department of Historical Sociology). Having previously studied a Bachelor's degree in Humanities and a Master's degree in Historical Sociology, both at Charles University, Prague, is currently working on a research project on autism in the Czech Republic from an historical sociological perspective. Simultaneously works as an assistant for clients with low functioning autism in APLA (Association in Aid of Persons with Autism). Previous academic activities include assistance on an historical sociological research project on the construction of elites in the Czech Republic and conducting empirical research as part of Master's degree, on the topic of the Czech dissent and cultural opposition during communism – a social group concentrated around *Revolver Revue*, the samizdat magazine, which was a part of the subculture called Czech Underground.

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### **The story of autism in the Czech republic: methodological and ethical aspects**

The paper will discuss the ethical and methodological challenges and pitfalls of the author's current research project in which he approaches autism as a social phenomenon and intends to reflect its history and the contemporary state in the Czech Republic. Three main areas of interest are pursued in the project from an historical sociological perspective: The development of the knowledge on autism produced by Czech experts from various disciplines and its implementation into practice; the Czech institutional network (available services, organizations, legislation etc.); the situation of people with autism and their families (their experience with services, the level of social stigmatisation, definition of main needs for changes etc.). Such a comprehensive approach seems to be needed since the project has an ambition to introduce the topic of autism into Czech sociology and also to offer a sociological contribution to the Czech interdisciplinary knowledge on autism. On the other hand, it is quite demanding for the project to remain coherent while pursuing these three layers which require various methodological strategies. This challenge will be discussed in the first part of the paper. Among the other methods of data collection, the research includes conducting interviews with people with high functioning autism and with parents of people with more severe forms of the disorder, as well as participant observation from the position of an employee in an NGO providing services to people with autism. It is necessary to carefully consider a lot of ethical aspects in these settings. These ethical dilemmas will be reviewed in the second part of the paper.



## Michelle Templeton

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Michelle graduated from Queen's University Belfast (1995) in Psychology, and took up a post in education working with young school leavers with little or no formal qualifications. During her time in this post she qualified as an NVQ Assessor and obtained a counselling degree from the University of Roehampton, London. She returned to Queen's to complete a Master of Philosophy in Psychology (MPhil) and was awarded a DEL Scholarship in 2012 to commence interdisciplinary PhD study within the School of Nursing and Midwifery and the School of Education. This has provided a unique opportunity to enrich her educational experience by becoming involved in two dynamic working networks across both disciplines. She is a member of the Maternal and Child Health research cluster and the 'Sexual Rights and Reproductive Health of Young People' special interest group and also a member of the 'Centre for Children's Rights' at Queen's which meets monthly and comprises researchers using participatory methodologies with children and young people. Her research interests include sexual rights and reproductive health of young people, and children's rights and participatory methodology in health research. She is keen to translate health research knowledge to inform health policy, education and practice that can generate change in health behaviours to improve children's lives.

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## Gaining Ethical Approvals to Undertake Sexual Health Research with Young People in the UK: Applying a 'Children's Rights Based Approach'

This paper (co-written with Dr Maria Lohan, Dr Carmel Kelly & Professor Laura Lundy) will describe the ethical review process to undertake health research in the UK, and explain an approach that can help researchers deal with ethical and methodological dilemmas in their research. Ethical review is necessary to ensure researchers and participants are protected, yet the requirement to 'pass' numerous committees may be challenging particularly for health researchers who work with vulnerable groups and sensitive topics. The inclusion of these groups/topics is crucial if health researchers are to understand health disparities and implement appropriate interventions with health benefits for vulnerable populations. It is proposed that to overcome ethical and methodological challenges and pitfalls, researchers must implement strategies that advocate for, and increase the participation of, vulnerable populations in health research. A 'children's rights based approach' using participatory methodology will be described that draws on the jurisprudence of international law, (United Nations Convention on the Rights of the Child, 1989) and provides a framework that may empower ethics committees to carry out their function confidently. The role of the researcher, framed within the context of doctoral level study, will be reviewed in terms of the investment required and benefits of utilising this approach. It will be argued that adopting this approach with vulnerable groups, not only guarantees their meaningful participation in the research process and permits their voices to be heard, but also offers ethics committees an internationally agreed upon legal framework, ratified by their governing States, from which to fulfil their obligations and resolve their ethical dilemmas. Increasing the representation and participation of vulnerable groups in health research can inform the development of health policy and practice based on 'insider knowledge' that better engages with and more adequately reflects their specific needs. This is likely to yield numerous health, social and economic benefits for all of society through the delivery of more equitable, effective and sustainable services.



Michelle Webster is a PhD candidate in the Centre for Criminology and Sociology at Royal Holloway, University of London. Her thesis focuses on experiences and management of childhood epilepsy in the family and encompasses the Sociology of Health and Illness, Sociology of Childhood, Sociology of the Family and Sociology of Food. She also holds a BA in Sociology and an MSc in Social Research from the University of Leicester

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### **The Difficulties of Accessing Children's Health Experiences**

It is widely acknowledged that gaining access to children is difficult due to the presence of gatekeepers. However, once access is gained, the researcher does not have automatic access to the children's health experiences. Although there is extensive literature regarding interviewing techniques and tasks that are intended to engage children and ensure their participation is enjoyable, children are active participants in social interactions and it is, therefore, not always straightforward to engage them in a subject they may not wish to discuss. This paper draws on research conducted for a doctoral thesis focusing on the experience and management of childhood epilepsy within the family. Group task-based interviews and individual auto-driven photo-elicitation interviews were conducted with children aged 6-16. It will be argued that children may feel stigmatised or different as a result of living with a particular condition and, consequently, may not wish to share their experiences. This was evident as children used discursive strategies to avoid answering questions. Given the unequal power balance between an adult researcher and a child participant, this paper argues that these blatant avoidance tactics left the researcher with the ethical decision about whether to continue probing children about topics they appeared uncomfortable discussing. Furthermore, it will be shown that even when children were happy to discuss their condition, it was still difficult to access children's health experiences due to language barriers. It will be demonstrated that children interpreted questions differently to the way in which they were intended and, equally, the researcher had difficulty interpreting some of the children's descriptive phrases. Overall, this paper suggests that research with children is contingent and open to (re-)negotiation; researchers must reflect on each interview in order to gain as much data as is ethically possible from subsequent interviews.



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I am a doctoral student in the School of Health Sciences, University of Tampere, Finland. The working title of my thesis is “Toward social integration of mentally-ill people in Post-Soviet Russia: A Socio-cultural perspective”. I have finished MA programme in the European University in St. Petersburg (Russia) in 2004. Before that I was graduated in medical psychology in Maimonid Jewish Moscow State Academy (Russia) in 1999. I had professional experience as a psychologist in the Vocational-Rehabilitation Centre for the disabled and in Children’s psychiatric hospital, St. Petersburg. Also I have worked as a sociologist in the Centre of Independent Social Research, St. Petersburg. During these roles I have been involved in a number of international projects such as “Health policy, values and changing society in Russia ”, “Support to the development of a system of primary health care facilities at federal and municipal levels” and others. My current research interests focus on Post-Soviet transformations, mental health policy as well as social integration and prevention of stigma.

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### **Doing qualitative research in post-Soviet mental health services**

The significant political and socioeconomic changes in Russia that occurred after the collapse of the Soviet Union have impacted mental health policy in the country. As part of this, the country demonstrated an intention to develop a new mental health policy based on approaches consonant with World Health Organization’s principles. The new approach stresses patients’ freedoms as a way of countering Soviet political abuses, paternalism and ineffectiveness. In my doctoral study I analyse how these new policy ideas and values are reflected and interpreted in health policy documents, mass-media, the mental health professionals’ community as well as by mental health services’ users. The study uses qualitative research methodology. In my talk I will highlight some methodological and ethical difficulties that I encountered when carrying out interviews with mental health professionals. I found that the topics of Soviet psychiatry and post- Soviet reforms are quite sensitive. I had significant difficulties in access to the research field as a researcher from a Finnish, e.g. Western University. My affiliation from one point of view encouraged interviewees to speak about the influence of international ideas on the reforms in Post- soviet psychiatry, but from another, raised their anxiety and provoked in some cases superficial answers. Speaking with the professionals I got an impression that they are afraid that their actions can be interpreted as infringing upon patients’ rights. Although I made it clear that participation is voluntary and anonymous professionals often refused tape recording. So I have methodological difficulties analyzing the data. From my point of view, the position of mental health specialists can be explained by the history of psychiatry in the Soviet Union as well as the anti-psychiatric campaigns that followed.





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I am currently a Postdoctoral Fellow at the Center for the History of Emotions at the Max Planck Institute for Human Development in Berlin, Germany. I defended my PhD dissertation at St. Petersburg Institute of History of the Russian Academy of Sciences in October 2013. After completing my undergraduate study at St. Petersburg State University (Department of Modern Russian History), I did my M.A. in History and Jewish Studies at Central European University in Budapest, Hungary. In my doctoral dissertation, I took a look at drug addiction and evolution of drug policy in Russia from 1917 to the end of the 1920s. I was particularly interested in explaining why (and how) Soviet authorities eventually decided that regulation of recreational drugs and compulsory treatment of drug addicts were necessary. My research interests include history of emotions, history of crime and legal history, history of alcohol and drugs, history of medicine and health care, social and cultural history of late Imperial and Soviet Russia, Jewish history, gender history, comparative history, digital humanities and urban and local history (especially the history of St. Petersburg). I have presented papers at the thematic conferences and participated in workshops in Russia, Finland, France, Germany, Sweden, Switzerland, United Kingdom and the United States. My publications include a book chapter on alimentary and pellagra psychoses in *Food and War in Twentieth-Century Europe* (Ashgate, 2011) and articles on addiction research in *Jewish Studies at the CEU* and *Social Justice: A Journal of Crime, Conflict and World Order*. For my research projects, I received funding from the Gerda Henkel Foundation (Düsseldorf, Germany) via its competitive Ph.D. Scholarship program, the Institute for Humane Studies (Humane Studies Fellowship, Hayek Fund for Scholars Award), Central European University, and the Government of St. Petersburg.

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### Dealing with Ethical Dilemmas in the History of Drugs

The purpose of this paper is to provide a historical perspective on dealing with ethical issues in research on health and illness, through the case study of the history of drugs – an inherently interdisciplinary and ethically problematic field. I am primarily interested in the history of drugs in late Imperial and early Soviet Russia, although I have recently started a project that involves discussion of drug abuse and drug policy in the Stalinist years and even more recent (and potentially more sensitive) period. Rita Charon has recently argued for an increased attention towards ethical issues in health research. In particular, she is very critical of the non-consensual use of sources and data that were produced in a setting where one side is *a priori* dominant and the other subaltern (such as a physician's office or a police precinct). What implications, then, does this observation have for historical research that often deals with primary sources produced in such settings and in most cases by definition can not obtain the permission of the respective actors? Can we reconcile this ethical imperative with the drive to give these oppressed people their voice in history? I would also discuss some issues arising from my experience in writing and publishing on such sensitive topics as drug history and drug policy. In particular, I am interested in the use of ethically appropriate terms in historical writing and the impact that historical writing has on various expert audiences (historians of drugs, medicine, and the Soviet Union; academics from neighboring disciplines; physicians and medical scientists; stakeholders in the legislatures, public health and the law enforcement agencies) and the general public.



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Robyn Lotto is currently a second year PhD student at the University of Leicester. Her project, “A study into the experiences of women and their partners, of care in pregnancies affected by a suspected severe fetal anomaly” is supported by the TIMMS (The Infant Mortality and Morbidity Studies) and SAPPHERE (Social Sciences Applied to Healthcare Improvement Research) groups. Robyn started her career as a nurse in 1994, having trained at the St. Bartholomew School of Nursing. She went on to specialise in cardiothoracic nursing and completed a specialist degree at the University of Southampton. Her interests in inequalities in health developed from there, and she went on to complete a Master’s degree in Health Sciences at the University of Newcastle. Her Master’s thesis involved looking at variations in care within the primary care setting. She has subsequently held a number of healthcare research positions in the UK and abroad. Her current project is particularly ethically challenging in relation to the subject matter, namely fetal anomalies and termination. This in turn raises a number of methodological challenges in terms of access and impact on participants.

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### **Termination of pregnancies due to fetal anomalies**

As a novice researcher, designing a qualitative study around the ethically sensitive and emotionally charged area of termination of pregnancies affected by suspected severe fetal anomalies has proved challenging. The lack of literature pertaining to women’s experiences following diagnosis or suspicion of a diagnosis of a severe congenital anomaly is perhaps a reflection of the ethical difficulties encountered by the research community when approaching such a sensitive topic, and subsequent avoidance of it. However, correspondence with authors of the few papers available has suggested that this has resulted in under-representation of a disenfranchised group, who are looking for a voice. Thus a number of ethical dilemmas have become pertinent when trying to balance the ethical principles of beneficence, non-maleficence, justice and autonomy throughout the research process. This article explores the experiences of a novice researcher navigating through the ethical and methodological minefields posed by a research study of a sensitive topic. Issues surrounding the collaboration with key stakeholders, as well as difficulties encountered with the blurring of roles between clinician and researcher are explored and reflected on. Recommendations made include addressing the dearth of literature exploring the needs of researchers undertaking studies encompassing sensitive topics. Similarly the frequent omission of governance processes to debate not only the potential risk to participants but also to those undertaking studies in areas of a sensitive nature must be recognised. Finally a celebration of the complementary roles of nurse and researcher is proposed.



Lic.Soc.Sc, MA, is a PhD candidate in philosophy in the Department of Behavioural Sciences and Philosophy at the University of Turku, Finland. Her thesis deals with philosophical questions concerning addiction, particularly questions about autonomy and action, and she teaches bioethics.

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### **Rethinking the research on heroin addiction**

My presentation (based on a paper co-written with a physician Barbara Broers) focuses on the question whether heroin addicts can give consent to research on trials in which heroin is prescribed to them as a form of treatment. In bioethical discussions this has been a matter of debate. The requirement for informed consent concerns the agent's competence and the notion of voluntariness. Heroin addiction has seen to undermine either or both of these aspects. The discussion has previously focused on heroin addicts' strong desires for the drug in the sense that they may be irresistible and thus problematizing the consenting. A recent article by Edmund Henden provides a new perspective on heroin addicts' options and voluntariness. This is a good start but I will question the plausibility of framing the options only in terms of heroin and access to it. As Henden and others have argued in light of empirical evidence, the problem is not whether the addicts' desires for heroin are irresistible. Yet the way in which the options are typically understood in this discussion revolve around an assumption that participation in the research is motivated by the addicts' views on using heroin. This kind of presentation fails to describe the actual options that the trials have had and bases on false assumptions of addiction and addicts. Furthermore, I also suggest that the account of voluntariness may do well without substantive criteria. The account need to realistic for subjects to be able to voluntarily give consent voluntarily and for medical research to develop addiction treatment in an ethical way.

## Join the Research Network on Sociology of Health and Illness (RN-16) and the European Sociology Association (ESA)

The Network embraces research on the impact of changing social, cultural and political factors on health within Europe and beyond. This includes but is not limited to themes such health inequalities, health systems, health professions, migration and health, risk, gender and health, ethnicity and health, bioethics, new genetics, embodiment, lay beliefs and illness accounts. Members' interests concern both physical and mental health and encompass theoretical as well as empirical research.

<http://europeansociology.org/research-networks/rn16-sociology-of-health-and-illness.html>

The RN-16 has a mailing list and a Newsletter, the purpose of which is to carry announcements of RN activities, conferences, books etc. relevant to the study of health and illness, facilitate exchange of information among list members and foster opportunities for collaborative research.

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**Do you want to find out about what is going on in sociology?** We will put you on our electronic mailing list which circulates information about jobs, scholarships, courses, conferences, meetings and summer schools. The newsletter of the association is published in hard copy three times a year and gives further news for sociologists.

**Do you want to find research partners?** Then join ESA which represents the largest network of sociologists in Europe.

**Individual Membership of the ESA** is open to the broad categories of all scholars who actively contribute to the scientific development of sociological knowledge in or on Europe. Regular membership is open to scholars who: carry out sociological research, teach sociology, have sociological jobs, are members of European national sociological associations or have academic degrees and training in Sociology. All members of the ESA receive not only the European Sociologist Newsletter, but also, if they are regular members, online copies of our journal European Societies (Routledge). And all ESA members pay significantly reduced fees when they register at our biennial conferences! Registration to ESA lasts two calendar years, with a tolerance of two months.

To become a member of the ESA, submit an electronic membership at:

<http://www.europeansociology.org/member/>

## **Renewal of RN-16 Membership**

Dear RN-16 members,

We will be very grateful if you could renew your membership. Please send an email to:  
[esa@europeansociology.org](mailto:esa@europeansociology.org) or [gisele.falcucci@europeansociology.org](mailto:gisele.falcucci@europeansociology.org)

Thank you.

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## **Changes of Address**

Dear RN-16 members,

In case you have changed your email address please let us know by sending an email to:  
[newsletter.rn16esa@gmail.com](mailto:newsletter.rn16esa@gmail.com)

Thank you.

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## **Welcoming of notices and Call for papers of interest for RN-16 members**

Your notices and Call for Papers that are of interest for RN-16 members are very welcome and must be sent as a word file; please note: no pdf files or email announcements will be considered!

Ana Patrícia Hilário & Micol Pizzolati

**RN-16 Newsletter Co-Editors**

E-mail: [newsletter.rn16esa@gmail.com](mailto:newsletter.rn16esa@gmail.com)